



SCOTTISH EXECUTIVE

Cancer Genetics Services in Scotland

Guidance to support the
Implementation of Genetics Services for
Breast, Ovarian and Colorectal Cancer
Predisposition

Scottish Cancer Group
Cancer Genetics Sub-Group

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EXECUTIVE SUMMARY

Breast, colorectal and ovarian malignant diseases are all common forms of cancer in Scotland. Recent medical advances have established that a predisposition to a number of these common cancers are caused by inherited genes. Although the proportion is small, the lifetime risk of cancer can be very high in susceptible subjects who have inherited predisposing genes. Thus it is of great importance to identify these persons and arrange that they, and other family members where appropriate, are screened for risk of developing cancer.

An historical difficulty in the screening process is the comparative rarity of these genetically-determined cancers: on average, any individual healthcare professional is unlikely to see more than 2 or 3 patients each year who have concerns relating to a family history of cancer. The large majority of such individuals will have their first clinical presentation in the primary care setting.

To ensure success in securing a robust and reliable genetics counselling and testing service for Scotland, Health Boards and Trusts will need to set in place dissemination systems which are capable of being monitored – to ensure that information on genetic forms of breast, ovarian and colorectal cancer is readily available to all healthcare professionals, notably general practitioners. As described in the guidance attached, such information must be accompanied by clear action plans and referral patterns required for each patient in whom the question of a genetically determined cancer has arisen.

Following identification in primary or secondary care, the onus is then placed upon supra-district services – the Regional Genetics Units (RGU) – to stratify such persons into low, medium or high-risk groups and on that basis, implement any necessary further action. To ensure that this is readily accessible throughout the country, the Scottish Executive has already provided funding for 5.5 Genetic Nurse Associates, who are employed by the regional genetics units with the specific objective of providing a service to patients referred with a family history of cancer.

National and uniform screening policies provide opportunities for the evaluation and audit of service delivery that is essential in initiatives of this nature. The Scottish Executive Health Department will establish a genetics sub-group to co-ordinate audit and allied activities. The Clinical Standards Board for Scotland will be involved as appropriate to their work programme.

1. SECURING A ROBUST, RELIABLE AND CO-ORDINATED CANCER GENETICS SERVICE

1.1 General considerations

The number of individuals predisposed to common cancers is small. Any individual clinician is unlikely to see more than 2 or 3 patients each year who have concerns relating to a family history of cancer. Since the majority of these contacts are made in primary care, it is important that the general practitioner has a clear framework for taking action in such cases.

Experience has shown that simple approaches (eg paper guidelines, didactic teaching) are at best only partially effective in the implementation process. A multi-faceted approach by health boards and trusts is therefore required to ensure that a reliable, co-ordinated strategy is in place.

1.2 Implementation in primary and secondary care

First contact is most likely to occur either in the general practitioner's surgery or in the hospital outpatient clinic setting (e.g. breast clinic, gastroenterology clinic). The education process for clinicians working in these areas should be designed to increase their awareness of the genetic element to some common cancers and give clear guidance as to how such cases should be handled. It will be important for health authorities to arrange local educational meetings or forums, which should be convened by specialists in clinical genetics and to which all relevant staff should be invited. It is essential for staff to be aware of the services provided by Genetic Nurse Associates and the roles that they play in assessing risk to the individual as well as assessing the family history.

Following identification of an at-risk patient or family, the clinician's first action will be referral, usually by letter, to the appropriate Regional Genetics Unit (RGU).

1.3 Implementation in secondary and tertiary care

Referral to the RGU should initiate the series of actions, which are summarised in the flowchart and led initially by the Genetic Nurse Associate. For those cases in which further action is contemplated, it will be necessary for the RGU to maintain and foster close contact with local colleagues (physicians, surgeons, oncologists etc) most likely to be involved in ongoing care. The RGU is also an ideal mechanism through which professional special-interest groups, e.g. breast and colorectal surgeons and gynaecologists, can become aware of their involvement in the screening and clinical management processes. Lead clinicians should be defined in each subspecialty to link with the cancer services managed clinical networks.

1.4 Implementation nationally (Scottish Executive Health Department)

Working through our Cancer Genetics Sub-group, the Health Department will provide further guidance in due course to ensure co-ordinated audit and allied activities are set in place. The Clinical Standards Board will be involved as appropriate to their work programme, with the aim of establishing a robust framework for assessment and

accreditation purposes. The sub-group will also ensure that any research proposals, which are designed to utilise data collected from the genetics screening services, will yield objective evidence and will not interfere with service delivery.

1.5 Flow Chart for Patient Management

The flow chart attached sets out the various roles and responsibilities actually required to ensure appropriate assessment and management of individuals who may be at increased risk of developing breast, colorectal and ovarian cancer based on their family history.

1.6 Guidelines for Implementation

The tables attached, set out in fuller detail the action required at each stage from referral to risk stratification through to management of low, medium and high risk individuals and follow-up in each tumour type.

2. Patient Management: A 5 Step Process

Step 1 Referral Process	Step 2 Confirmation of Family History	Steps 3 & 4 Risk Stratification & Counselling	Step 5 Management
<ul style="list-style-type: none"> ➤ Referrals of individuals with family/ personal history of cancer may come from GP's or other clinicians. ➤ Most referrals will come direct to the RGU and this is the preferred route to prevent inappropriate referrals to clinics such as the symptomatic breast clinic. ➤ Where possible the Genetic Nurse Associates should preview the referral letters and apply the guidelines classifying low, medium and high risk as appropriate ➤ Referrals falling outside the current guidelines but possibly suggestive of a high risk situation should be discussed with the consultant in charge of the RGU. 	<ul style="list-style-type: none"> ➤ Genetic Nurse Associates should contact referred individuals prior to their first full appointment to obtain a full history with details of cases of cancer in the family. ➤ Where possible, deceased cases should be confirmed using an appropriate source such as the Scottish Cancer Registry ➤ Consent should be sought for living affected to confirm and specify diagnosis and a full pedigree produced with risk calculation by a standard genetic analysis (CYRILLIC 3) for audit purposes 	<ul style="list-style-type: none"> ➤ Specific guidance on risk stratification and counselling for breast, ovarian and colorectal cancer is set out in the tables attached identifying individuals who should be classified as: ➤ Low risk (not fulfilling a category within the guidelines) ➤ Medium or high risk (fulfilling the criteria) <p><i>Notes</i></p> <ol style="list-style-type: none"> 1. Clearly as family history evolves and is confirmed or refuted, individuals may move from apparent high risk to medium or low and vice versa. 2. It is also important that families are encouraged to recontact RGU if family history changes following initial counselling. 	<ul style="list-style-type: none"> ➤ Specific guidance on the management of low, medium and high risk individuals for breast, ovarian and colorectal cancer is set out in the following tables. ➤ The management of all individuals is carried out through a process of gene testing and where possible surveillance. ➤ For high risk individuals, surgical management may be considered. <p><i>Note</i></p> <ol style="list-style-type: none"> 1. It is anticipated that Cancer Managed Clinical Networks will include individuals with specific expertise in the surgical management of cancers in high risk individuals.

A flow chart, mapping the patient pathway from referral through to management is contained overleaf.

**CANCER GENETICS SERVICES IN SCOTLAND
3. FLOW CHART FOR PATIENT MANAGEMENT**

Step 1 – Referral Process

General Practitioner or other Clinician (e.g. Breast Clinic) → PATIENT (preferred route of referral for all at risk)

Refer back to GP Or other clinician

LETTER OF REFERRAL TO REGIONAL GENETICS UNIT (or associated clinics)

Letters previewed and criteria applied (by Associate/Nurse)
High/Med/Low using 'SIGN' Guidelines

**Step 2
Confirmation of Family history**

ASSESSMENT BY GENETIC NURSE ASSOCIATE

- 1) By letter (or by)
- 2) telephone
- 3) consultation

FAMILY HISTORY EVALUATION

- a) Confirmation of deceased cases
- b) Obtain consent from living cases to confirm history
- c) Prepare Pedigree (+ Cyrillic risks for Audit)

RISK ASSESSMENT BY GUIDELINE - Breast
Ovarian
Colorectal

**Step 3
Risk Stratification**

LOW RISK

MEDIUM RISK

HIGH RISK

Letter of reassurance to Patient and GP (or other referring clinician)

(Confirming family history may move into different risk groups). May also include complicated family history.

**Step 4
Counselling**

Counselled by Genetic Counsellor (with aid of support information sheets)

Counselling by Clinical Genetic Physician

**Step 5
Management**

Surveillance/Follow Up

Gene Testing

Management/follow Up

4. Breast Risk Stratification and Counselling

Low	Medium	High
<i>Risk Stratification</i>	<i>Risk Stratification</i>	<i>Risk Stratification</i>
<ul style="list-style-type: none"> • Anyone not fulfilling medium or high risk criteria 	<ul style="list-style-type: none"> • One 1st degree relative with bilateral breast cancer (BrCa) • One 1st degree relative with BrCa<40yrs or male at any age • Two 1st or 1st and 2nd degree relative with BrCa diagnosed under 60yrs or OvCa at any age on the same side of the family • Three 1st or 2nd degree relatives with BrCa or OvCa on same side of family (at least one 1st degree relative unless history via father) 	<ul style="list-style-type: none"> • Gene carriers (eg BRCA1, BRCA2, p53, pTEN) • Untested 1st degree relatives of gene carriers • Women with first degree relative (or 2nd degree via intervening male relative) in a family with 4 or more relatives affected with breast cancer (bilateral breast cancer being counted as 2) or ovarian or male breast cancer in three generations • Women with one first degree relative (or 2^d degree via intervening male relative) with breast and ovarian cancer
<i>Counselling</i>	<i>Counselling</i>	<i>Counselling</i>
<p>Individuals deemed at low risk will be informed either by:</p> <ul style="list-style-type: none"> • Telephone consultation with the genetic nurse associate, followed by letter with a copy to GP, or • Face to face consultation with the genetic nurse associate and then by letter to the patient and the GP • Individuals deemed to be to low risk may be offered a single appointment for breast examination by a surgeon in certain centres. The effect of the intervention on satisfaction will be assessed. 	<p>Individuals deemed to be at medium risk will be counselled by the genetic counsellor, who will discuss with them information as recorded in Appendix 1.</p>	<p>Individuals deemed to be at high risk will be counselled by the clinical genetic physician.</p>

4. Breast Management

Low Risk	Medium Risk	High Risk
<ul style="list-style-type: none"> • Reassurance • Healthy lifestyle advice • Return to GP Care • Advise to report any symptoms or changes in family history • If family history of breast cancer, letter and leaflet of Breast Awareness for female patients 	<p>Mammogram (and ultrasound as appropriate) at Breast Screening Centre as follows:</p> <ul style="list-style-type: none"> • 2 yearly intervals for women aged 35-40 yrs • Annually for women aged 40-50 yrs • Thereafter, women enter the national screening programme and are screened at 3 yearly intervals until 64. • Physical examination by Breast Clinician annually for women aged 35-50 yrs <p><i>(Screening from 5 years younger than the youngest case but not younger than 35yrs or older than 40yrs as indicated)</i></p>	<p>Mammogram (and ultrasound as appropriate) at Breast Screening Centre as follows:</p> <ul style="list-style-type: none"> • 2 yearly intervals for women aged 25-40 yrs • Annually for women aged 40-50 yrs. • Every 18 months for women aged 50-64 yrs, through Breast Screening Programme • Every 3 years for women aged over 65 • Physical examination by Breast Clinician annually for women aged 25-64 yrs <p><i>(Screening from 5 years younger than the youngest case but not younger than 25yrs or older than 35yrs)</i></p> <p style="text-align: center;">Gene Testing</p> <p>Following counselling by a clinical genetics physician, gene testing should be available to all high-risk families and predictive testing offered to all at risk individuals within these families.</p>

Surgical Management: High Risk Individuals
<ul style="list-style-type: none"> • In unaffected women, continued screening will probably be the preferred option but prophylactic surgery may be considered in particularly high risk cases. • Affected individuals are offered the range of surgical and other therapeutic options as appropriate. These include lumpectomy followed by radiotherapy or chemotherapy; mastectomy with preservation of nipple and subsequent adjuvant therapy; reconstructive surgery; contralateral prophylactic surgery; prophylactic oophorectomy. <p>(It is anticipated that Cancer Managed Clinical Networks will include individuals with specific expertise in the surgical management of cancers in high risk individuals)</p>

5. Ovarian Risk Stratification and Counselling

Low	Medium	High
<i>Risk Stratification</i>	<i>Risk Stratification</i>	<i>Risk Stratification</i>
<ul style="list-style-type: none"> • Anyone not fulfilling medium or high risk criteria • Individuals with a single 1st degree relative or 2nd degree relative by their father who have presented at any age, are not appropriate for screening 	<ul style="list-style-type: none"> • Two or more 1st or 1st and 2nd degree relatives with OvCa at any age; • Two 1st or 1st and 2nd degree relatives with OvCa at any age or BrCa diagnosis under 50yrs (i.e. one of each type of cancer); • One OvCa and two breast cancers diagnosed less than 60yrs on same side of family in 1st degree relatives or 2nd degree relatives via a male • Two 1st or 2nd degree relatives with CRC and an endometrial Ca and one OvCa • One affected relative with OvCa and HNPCC family history 	<ul style="list-style-type: none"> • Women in a family where BRCA1, BRCA2, hMLH1, hMSH2 or other predisposing gene has been identified • Untested 1st degree relatives of gene carriers • A woman with at least one 1st relative with breast and ovarian cancer
<i>Counselling</i>	<i>Counselling</i>	<i>Counselling</i>
<p>Individuals deemed at low risk will be informed either by:</p> <ul style="list-style-type: none"> • Telephone consultation with the genetic nurse associate, followed by letter with a copy to GP, or • Face to face consultation with the genetic nurse associate and then by letter to the patient and the GP 	<p>Individuals deemed to be at medium risk will be counselled by the genetic counsellor, who will discuss with them information as recorded in Appendix 1.</p>	<p>Individuals deemed to be at high risk will be counselled by the clinical genetic physician.</p>

5. Ovarian Management

Low Risk	Medium Risk	High Risk
<ul style="list-style-type: none"> • Reassurance • Healthy lifestyle advice • Advise to report any changes in family history promptly • Return to GP Care 	<p>Screening is performed from 35 yrs of age or 5 yrs younger than the youngest affected member of the family) This should include:</p> <ul style="list-style-type: none"> • Appointment with a Gynaecologist/Oncologist – if possible • Yearly Ultrasound • Yearly Ca 125 estimation • Discussion of prophylactic oophorectomy • Entry into UKCCCR Trial (if women have a history of both breast and ovarian cancer, or a family history of only ovarian cancer or family history consistent with HNPCC with ovarian cancer in the family) <p>[The limitations of ovarian screening should be explained to all women in this category].</p>	<p>Such women are screened as for medium risk. Screening is performed from 35 yrs of age or 5 yrs younger than the youngest affected member of the family. This should include:</p> <ul style="list-style-type: none"> • Appointment with a Gynaecologist/Oncologist – if possible • Yearly Ultrasound • Yearly Ca 125 estimation • Discussion of prophylactic oophorectomy • Entry into UKCCCR Trial (if women have a history of both breast and ovarian cancer, or a family history of only ovarian cancer or family history consistent with HNPCC with ovarian cancer in the family) • Depending on family history it may be appropriate to offer screening of other organs. <p>[The limitations of ovarian screening should be explained to all women in this category].</p> <p style="text-align: center;">Gene Testing</p> <p>Following counselling by a clinical genetics physician, gene testing should be available to all high-risk families and predictive testing offered to all risk individuals within these.</p>

Surgical Management: High Risk Individuals
<ul style="list-style-type: none"> • In unaffected women, continued screening will probably be the preferred option but prophylactic surgery may be considered in particularly high-risk cases • Affected women are treated along conventional lines as for best management of sporadic ovarian cancer. <p>(It is anticipated that Cancer Managed Clinical Networks will include individuals with specific expertise in the surgical management of cancer in high risk individuals)</p>

6. Colorectal Risk Stratification and Counselling

Low	Medium	High
<i>Risk Stratification</i>	<i>Risk Stratification</i>	<i>Risk Stratification</i>
<ul style="list-style-type: none"> • Anyone not fulfilling medium or high risk criteria 	<ul style="list-style-type: none"> • One 1st degree relative affected by colorectal cancer when aged <45yrs • Two (one affected at less than 55 yrs) one a 1st degree relative subject • Three affected with colorectal or endometrial cancer who are 1st degree relatives of each other and one a first degree relative of subject • Two affected 1st degree relatives (one affected at less than 55 yrs) 	<ul style="list-style-type: none"> • Gene carriers of HNPCC mutation • Untested 1st degree relatives of gene carriers • People with a family history compatible with HNPCC (at least 3 family members affected by CRC or at least 2 with CRC and one with endometrial cancer in 2 or more generations; one affected relative must be affected at 50 years or less; one of the relatives must be a first degree relative of the other two).
<i>Counselling</i>	<i>Counselling</i>	<i>Counselling</i>
<p>Individuals deemed at low risk will be informed either by:</p> <ul style="list-style-type: none"> • Telephone consultation with the genetic nurse associate, followed by letter with a copy to GP, or <p>Face to face consultation with the genetic nurse associate and then by letter to the patient and the GP.</p>	<p>Individuals deemed to be at medium risk will be counselled by the genetic counsellor, who discuss with them information as recorded in Appendix 2.</p>	<p>Individuals deemed to be at high risk will be counselled by the clinical genetic physician.</p>

6. Colorectal Management

Low Risk	Medium Risk	High Risk
<ul style="list-style-type: none"> • Reassurance • Healthy lifestyle advice • Advise to report any changes • Return to GP Care 	<p>Screening comprises:</p> <ul style="list-style-type: none"> • A single colonoscopy at 30-35 yrs, if findings are normal this need not be repeated until 55 yrs of age. • Incomplete colonoscopy should be followed by a barium enema, preferably at same hospital attendance 	<p>Screening comprises:</p> <ul style="list-style-type: none"> • Colonoscopy every 2 yrs from age 30 or 5 yrs younger than the youngest affected, up until the age of 70. • Discussion of prophylactic surgery, if recurrent polyps are identified – total colectomy, with rectal sparing and ileorectal anastomosis is the best option • Consideration needs to be given to screening for other cancers which may occur in specific families and are part of the HNPCC spectrum <p style="text-align: center;">Gene Testing</p> <p>Following counselling by a clinical genetics physician, gene testing should ideally be available to all high-risk families and predictive testing offered to all at risk individuals within these families.</p>

Surgical Management: High Risk Individuals

- In unaffected individuals, continued screening will probably be the preferred option but prophylactic surgery may be considered in particularly high-risk cases where recurrent polyps are identified on repeat screening
 - Affected subjects should undergo resection of tumour with a major portion of contiguous bowel to decrease the risk of other tumour recurrence. Adjuvant therapy may subsequently be used and regular surveillance of any remaining large bowel is essential.
- (It is anticipated that Cancer MCN's will include individuals with specific expertise in the surgical management of cancers in high risk individuals)

Management: Patients with Established Colorectal Cancer

These individuals require more extensive resection to reduce risk of metachronous tumours. Colonic tumour is best treated by colectomy with ileorectal anastomosis; surgery for rectal cancer usually comprises extensive left hemi-colectomy with anterior resection.

Consideration also needs to be given to screening for other cancers which may occur in specific families and are part of the HNPCC spectrum., details of these are set out overleaf:

Other Cancers:

Endometrial and Ovarian Cancer

Discuss annual gynaecological screening. There is no established method for endometrial cancer screening and no available data on efficacy. Some centres offers clinical examination, transvaginal ultrasound and pipelle endometrial biopsy. Experience in familial ovarian cancer indicates ovarian screening is of doubtful efficacy. There is a good case to avoid screening outwith research studies.

Discuss prophylactic hysterectomy and bilateral oophorectomy – should be done by a gynaecologist and full-operative discussion of surgical/risks potential benefits is essential. There is no clear evidence for benefit, but surgery may be preferable to pelvic screening for women past reproductive age, particularly if there is any history of gynaecological cancer in the family.

Gastric Cancer

Offer 2 yrly upper GI endoscopy, contemporaneous with colonoscopy – aged >50 yrs or 5 yrs younger than the first case in family. No available data on benefit, so a good case to recommend no screening outside trials.

7. OTHER ISSUES

7.1 Psychological Support

An appointment with a clinical psychologist or other appropriately trained individual should be offered to:

- Anyone undergoing predictive testing for mutations in cancer predisposing genes known to exist in families
- Anyone considering prophylactic surgery
- Any individual with signs or symptoms of clinically significant psychological disturbance.

7.2 Clinical Trials

All patients should be invited to participate in current on-going studies, which include:

- MRI Breast Screening Trial (MARIBS)
- International Breast Cancer Intervention Study – Tamoxifen (IBIS) and successor trials
- Epidemiology of BRCA1 & 2 Mutation Carriers (EMBRACE)
- National Familial Ovarian Cancer Screening Study (UKCCRCR)
- Colorectal Cancer Genetic Susceptibility Study (COGS)
- Concerted Action for Polyp Prevention (CAPP2)

7.3 Education

This guidance for referral and screening risks, as well as for screening protocol should be made available to general surgeons, oncologists, gastroenterologists, radiologists and gynaecological oncologists in all NHS Trusts in Scotland.

Information for clinicians on referral criteria, and on recommendations for risk cut-offs for screening, and screening protocol should be provided by appropriate routes including the Scottish Cancer Group and other relevant bodies.

Relevant under-graduate, postgraduate and other bodies responsible for education and training should ensure a planned programme of ongoing education for medical students and all qualified medical staff and relevant paramedical staff.

Implementation may play a part in the education process and will be facilitated following advice from the Scottish Cancer Group.

7.4 Quality Assurance

These broad guidelines for referral, risk estimation management and audit should be regarded as the appropriate process for cancer genetic referrals in Scotland. Quality assurance of this process may be assessed by yearly evaluation of random case records from each counsellor and clinician in each centre. This data should be provided in an anonymised form to the co-ordinating committee yearly.

7.5 Audit

Audits should be carried out within the Regional Genetics Units and should include the downstream management facilities within Scotland. In addition to local audit process in the Regional Genetics Unit, audit of screening and outcome should be performed. The Clinical Standards Board for Scotland may subsequently assess services and key items of audit will underpin this process. Audit will also underpin Clinical Governance of this group of services, in particular continuous self assessment.

7.6 Cancer Registration

Confirmation of cancer history can be obtained from the cancer registries. For living individuals, a consent forms signed by that individual must be obtained and requests passed to appropriate Regional Genetics Service and hence to Cancer Registry.

Yearly assessment of cancers occurring in individual referrals to the cancer genetics service will be possible by supplying Scottish Cancer Registry with information on relevant individuals from the previous year in a cumulative file (i.e. each year give all of the previous years consultands since the initiation of the prospective study).

Information which may be provided on the consultands includes: Name, DOB, NHS NO., CHI Number, Postcode. The information can be provided on disc or Zip file in Access or plain text (for guidance on confidentiality of personal health information refer to HDL (2001) 1).

7.7 Database Management

Databases for collecting genetic clinic data will need to undergo regular quality assurance. ISD may inform this process with SMR Data standards e.g. QA sample of data annually. It will be necessary to ensure that all of the data collected is backed up in an appropriate manner and that the back up is safely stored in a fire and theft proofed manner. Sequential back up is recommended so that data from 1 week or 1 month previously can be used if any corruption enters the system. Future plans need to be made for the central archiving of all data.

Appendix 1:

Discussion Points for Breast and Ovarian Cancer

NAME:	STUDY NUMBER:
Discussion at clinic visit for Breast	Appointment Date
Genetic Risk	
Family Genetic Risk	
Breast Cancer Testing	
Healthy Lifestyle	
Oral Contraception Pill	
Hormone Replacement Therapy	
IBIS or successor	
Breast Self Examination	
Others	
Screening Recommendations	Clinical Examination Date Mammography Due
Awaiting Information from Cancer Registration	

Appendix 2:

Discussion Point for Colorectal Cancer

NAME:	STUDY NUMBER:
Discussion at clinic visit for Bowel	Appointment Date
Genetic Risk	
Family Genetic Risk	
Gene Testing	
Healthy Lifestyle	
Family Member who could supply DNA	
Patient will discuss with relative	Yes No
Patient will supply Patient Name, Address and GP's name and address	Will Send Will Call Dept
Information Received	Date
Information Sent to	Patient GP Date
Screening Recommendations	Colonoscopy Yes No Date of referral to for colonoscopy
Awaiting Information from Cancer Registration	